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Abstract

Background: Palliative care needs are increasing as more people are dying from incurable diseases. Healthcare costs have been reported to be highest during the last year of life, but studies on the actual costs of palliative care are scarce.

Aim: To explore the resource use and costs of palliative care among end-stage breast, colorectal and prostate cancer patients after termination of life-prolonging oncological treatments, that is, during the palliative care period.

Design: A real-life longitudinal register- and questionnaire-based study of cancer patients' resource use and costs.

Participants: In total, 70 patients in palliative care with no ongoing oncological treatments were recruited from the Helsinki University Hospital or from the local hospice. Healthcare costs, productivity costs and informal care costs were included.

Results: The mean duration of the palliative care period was 179 days. The healthcare cost accounted for 55%, informal care for 27% and productivity costs for 18% of the total costs. The last 2 weeks of life contributed to 37% of the healthcare cost. The costs of the palliative care period were higher in patients living alone, which was mostly caused by inpatient care ($p=0.018$).

Conclusion: The 45% share of indirect costs is substantial in end-of-life care. The healthcare costs increase towards death, which is especially true of patients living alone. This highlights the significant role of caregivers. More attention should be paid to home care and caregiver support to reduce inpatient care needs and control the costs of end-of-life care.

Keywords

Breast cancer, colorectal cancer, prostate cancer, palliative care, end-of-life care, costs, health economics

What is already known about the topic?

- Costs during the last months of life are in cancer patients substantial, but the true costs of the palliative care period are poorly described.
- In addition to healthcare needs, the share of informal care is significant during end-of-life care.

What this paper adds?

- Indirect cost (informal care and productivity loss) explains approximately half of the total cost of palliative care period.
- The last 2 weeks of life with increasing inpatient costs are the most expensive ones, especially in patients living alone.

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Implications for practice, theory or policy

- More attention should be paid on home care and caregiver support to control the end-of-life care costs.
- Special arrangements are needed to support home care of patients living alone to reduce inpatient care needs.
- The specific cancer treatment expenses should be separated from palliative care costs to be able to focus on how palliative care services have affected the costs.

Introduction

The increasing need for good quality end-of-life care has been a recurrent theme of medical discussion during the last decades. The need for palliative care is expected to escalate as the population ages. The rate of increase in the healthcare costs (HCCs) exceeds that of economic growth in the developed countries¹ generating new concerns. As resources are limited, reliable cost data become necessary for healthcare management and planning.² The total economic burden of cancer in Europe was assessed to be €126 billion in 2009,³ but the cost of cancer care after termination of life-prolonging oncological treatments, that is, during the palliative care period of cancer is poorly documented.⁴

In general, palliative care interventions are found to lower the costs compared to usual care, and early integration of palliative care into oncology has improved quality of life and diminished aggressive treatments at the end stage of life.^{5–7} However, the cost savings are mainly calculated for HCC as the total costs of palliative care are difficult to estimate if, for example, only hospital registries are used.⁸ In palliative care, the role of informal caregivers (informal care) is significant^{9,10} and disablement creates productivity costs.^{11,12} As stated above, there is relatively little generalizable knowledge of the true costs of the palliative care period as previous studies have concentrated mostly on the last months of life, including not only palliative care costs but also cancer-specific treatment expenses. Furthermore, most studies have been performed in a North American environment.^{13–16}

Breast cancer, colorectal cancer and prostate cancer account for 24% (42.6 deaths/100,000) of the Finnish annual cancer mortality, and within the next 10 years over 20,000 people will succumb to these cancers in Finland.¹⁷ Therefore, patients with breast, colorectal or prostate cancer can be used to describe the typical treatment trajectory after termination of life-prolonging oncological treatments, that is, during the palliative care period of cancer in Finland.

The aim of this study is to scope the cost formation of palliative care in cancer patients after oncological life-prolonging treatments have been terminated. All the relevant cost elements, HCC, productivity cost and informal care cost, were considered. In addition, the demographic factors associated with elevated costs were explored.

Patients and methods

This study is part of a research project exploring the costs and health-related quality of life (HRQoL) in 2000 breast, colorectal and prostate cancer patients in different stages of the disease. The patients were recruited from the Cancer Centre of Helsinki University Hospital and the local hospice in Helsinki (Terhokoti) between September 2009 and April 2011. The study protocol was approved by the Ethics Committee of the Helsinki and Uusimaa Hospital District (trial number: 233895; www.hus.fi), and written informed consent was obtained from every patient before inclusion. The study is a longitudinal register- and questionnaire-based study of cancer patients' resource use and costs. The study design and quality-of-life results have been reported in detail previously.^{18,19}

Patients

Inclusion criteria were as follows: age over 18 years, metastatic disease and patients were to receive no life-prolonging oncological treatments, like chemotherapy or targeted therapies documented in patient records. In total, 70 patients fulfilling the inclusion criteria were recruited.

Definition of palliative care period. The palliative care period was defined as a period of time after termination of cancer-specific disease modifying or stabilizing, that is, life-prolonging, treatments like chemotherapy or biological treatments.

Data collection

All the resource use and costs were recorded throughout the palliative care period. Costs were divided into HCC, productivity costs and informal care costs. Costs were recorded in Euros according to the 2010 price level. The cost data were obtained from the registers of the National Social Insurance Institution of Finland (SII), the Helsinki and Uusimaa Hospital District and the administrative databases of the cities of Helsinki, Espoo and Vantaa, which are the three largest cities of the hospital district. Resource use and unit cost data were also available from the local hospice. The respondents' clinical background information regarding diagnosis and treatments during the palliative care period, and the date of death, were determined from patient records.

Primary healthcare services are organized by communities. Costs of general practitioner and nurse visits, home hospital and hospice care and primary care hospitalization were available for 61 of the 70 patients who lived in the communities of Helsinki, Espoo or Vantaa, comprising over 85% of the study population. Secondary and tertiary health care in Finland is organized by municipalities through hospital districts. Data on resource use and costs were retrospectively collected from the records of the Helsinki and Uusimaa Hospital District. Data on visits to private practitioners and their costs and the number of journeys and their costs were available from the SII registries. If the costs of travel to the place of treatment exceeded the patient's maximum co-pay, €14 per visit, it was also included.

Patients also received a questionnaire from the hospital, from the hospice or by mail. In the questionnaire, the recipients were asked whether they were married or living together with a spouse in a common-law marriage. They were also asked to recall the number of hours per week of care and support they received from family or friends in the previous 3 months. The maximum daily hours were limited to 16 h. Patients also recorded whether they had retired from working life due to cancer.

HCCs

Inpatient costs. The inpatient costs include treatment costs at communal facilities, tertiary care hospitals or hospice care. The data contained information on the day on which the hospital visit started and ended, diagnosis and procedure code and patient-level costs including all supplementary costs such as drugs used during inpatient care.

Outpatient costs. The outpatient costs include outpatient visits, home hospital and home hospice care, together with medication, travel and care received at private facilities. As outpatient medication in Finland is reimbursed by the SII, reliable data on outpatient medication usage and costs were available from the SII registers.

HCC during the last 12 weeks of life. The medical costs from hospice, communal and hospital care were divided into 2-week periods, for the last 12 weeks of life. As the duration of palliative care period varied from patient to patient, the calculation of mean cost of each week was made manually. Outpatient medication was excluded from the costs, as it is often involved higher spending on medication for a longer period of time.

Productivity costs

Productivity loss is defined as a reduction of productivity during the days absent from work due to cancer. We used the most commonly employed human capital approach to

value productivity. The margin of production of the individual is valued at his or her pre-tax salary.²⁰ The productivity loss was then accounted for by multiplying the number of days absent from work by the average daily labour cost, including the employer's social security payments of on average 38.6% in addition to the pre-tax salary. The daily salary for the patients was calculated from salary-based sickness benefits, available from the SII.

Informal care

Informal care is by definition care given free by family or friends because of a family member's or friend's disability or illness. The amount of informal care was estimated by the patients in the questionnaires. The valuation was based on the proxy good method²¹ which values the time spent on supporting a patient at the shadow price of a market substitute. We applied the mean hourly pre-tax salary of €13.63 for a practical nurse in 2010.²² The hourly labour cost was then calculated by adding 38.6% social security payments for employers to the pre-tax salary, which yielded the final cost of €18.89 per hour used in the analysis.

Data analysis

The differences in the costs are reported with 95% confidence intervals (CIs), when practical. The stepwise log-linear multivariate analysis was used to explore the associations of background factors with the HCCs. Due to the skewed distribution of the HCC, the dependent variable was the ln (natural logarithm) of the HCC. Explanatory variables entered were cohabiting status, education level, duration of palliative care period in days, breast cancer and prostate cancer. Gender correlated with cancer type and thus was not included in the analysis. When mean values were compared, independent samples *t*-test was utilized. A risk level of 5% was used for type 1 errors in all the analyses. The analyses were performed with SPSS 20 software (SPSS Inc., Chicago, IL, USA).

In the case that communal data were inaccessible (nine patients), we imputed the missing value with the defined cancer groups' average primary care cost. The missing questionnaire answers concerning informal care were imputed with mean cost of informal care.

Results

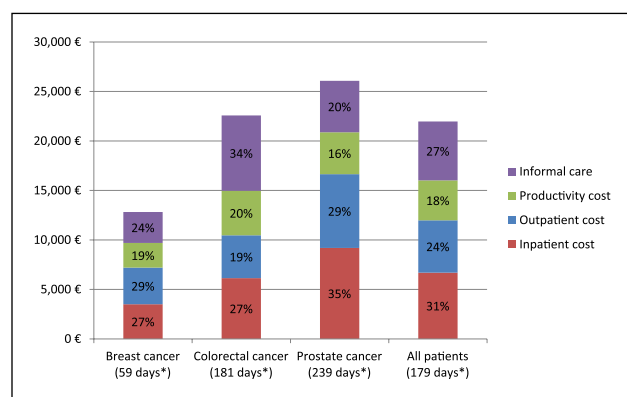
Patient characteristics

Of the 311 cancer patients fulfilling the inclusion criteria and invited to participate, 115 (37%) patients responded. For 70 (23%) of them, cost records were available. Characteristics of the patients are presented in Table 1. Prostate cancer patients were older, less educated and

Table 1. Patient characteristics.

	Breast cancer	Colorectal cancer	Prostate cancer	All patients
Respondents (%)	13 (19)	33 (47)	24 (34)	70 (100)
Age, mean in years (range)	64 (35–81)	68 (48–86)	74 (56–87)	69 (35–87)
Female (%)	13 (100)	14 (42)	0 (0)	27 (39)
Higher education (%) ^a	8 (62)	18(56)	9 (38)	35 (51)
White-collar employment (%) ^a	8 (62)	21 (66)	15(39)	44 (64)
Married/cohabiting (%) ^a	6 (50)	21 (66)	17 (73)	44 (66)
Mean duration of palliative care period in days (95% CI)	59 (17–101)	181 (110–253)	239 (161–318)	179 (134–223)
Mean time in years from metastasis to palliative care period (range)	4.0 (1.4–15.5)	1.6 (0.2–10.1)	2.8 (0–15.2)	2.4 (0–15.2)

CI: confidence interval.

^an = 67, three non-respondents to background questions.**Figure 1.** Mean cost of the palliative care period in Euros in different cancer types.

*Mean length of palliative care period.

more often married than breast and colorectal cancer patients. The duration of the palliative care period varied between cancer types being longest in prostate cancer (239 days, 95% CI: 161–318) and shortest in breast cancer (59 days, 95% CI: 17–101).

Resource use and cost components

The costs of the palliative care period are presented in Figure 1 and Table 2. HCCs were highest covering 55% of the total costs, followed by informal care costs (27%) and costs due to productivity loss (18%). The mean number of outpatient visits was 13.1 (95% CI: 9–17) and 43 patients (61%) were hospitalized for a mean of 11.6 days (standard deviation (SD), 17.6) during the palliative care period.

Only six patients used private health care, and these visits formed only 0.1% of the total HCC.

The mean weekly informal care received was 11 h. Productivity costs were incurred by only 15 patients (21%). In patients under 68 years of age (the general maximal retirement age in Finland), the proportion of productivity cost was 38%.

The costs in different cancer types are presented in Figure 1. The total costs were lowest in breast cancer, which also had the remarkably shortest duration of palliative care period. The costs of the last 60 days of life were €6096 in breast, €6085 in colorectal and €5306 in prostate cancer.

The increase in the HCC towards death is shown in Figure 2. In the total population, the last 2 weeks of life accounted for 37% of the HCC of the whole palliative care period.

Factors associated with HCCs

In multivariate analysis, living alone was the only socioeconomic factor ($p=0.006$) associated with elevated costs. Other factors significantly associated with higher HCC were age ($p=0.014$) and prostate cancer ($p=0.001$) (Table 3).

Costs of cohabiting and patients living alone are presented in Figure 3. Mean inpatient costs were significantly higher in patients living alone compared to cohabiting patients (€11,013 vs €4879, $p=0.018$), and there was also a trend of increased total HCC in the patients living alone (€17,642 vs €9614, $p=0.059$). The mean number of inpatient days was 7.1 versus 21.6 and outpatient visits were 10.1 versus 19.8 in cohabiting and non-cohabiting patients, respectively. The HCC during the last 12 weeks of life in patients living alone and cohabiting ones are presented in Figure 3.

Discussion

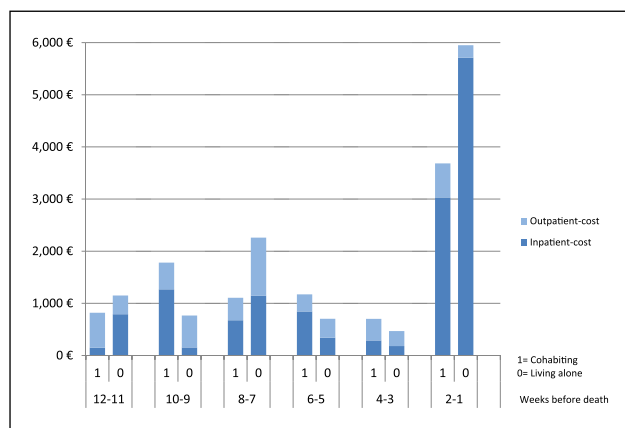
Main findings

In this study, we found that the HCCs account for only a half of the total cost of the palliative care period after termination of life-prolonging treatments in cancer patients, while the informal care costs were substantial. In addition, the HCCs were significantly higher in patients living alone.

Table 2. Mean cost, units and duration of palliative care period.

Cancer type	Breast cancer	Colorectal cancer	Prostate cancer	All patients
Mean duration of palliative care period (days)	59	181	239	179
Total cost in Euros (95% CI)	12,825 (3631–22,019)	22,576 (10,468–34,684)	26,080 (18,974–33,185)	21,966 (15,670–28,262)
Outpatient cost (95% CI)	3698 (1085–6310)	4334 (2689–5979)	7453 (5619–9286)	5286 (4165–6405)
Inpatient cost (95% CI)	3505 (258–6752)	6137 (2992–9281)	9191 (5869–12,513)	6695 (4753–8637)
Productivity cost (95% CI)	2492 (34–4949)	4502 (21–8983)	4231 (0–9169)	4035 (1390–6681)
Informal care (95% CI)	3130 (0–7278)	7604 (0–15,541)	5205 (2704–7706)	5951 (2141–9760)

CI: confidence interval.

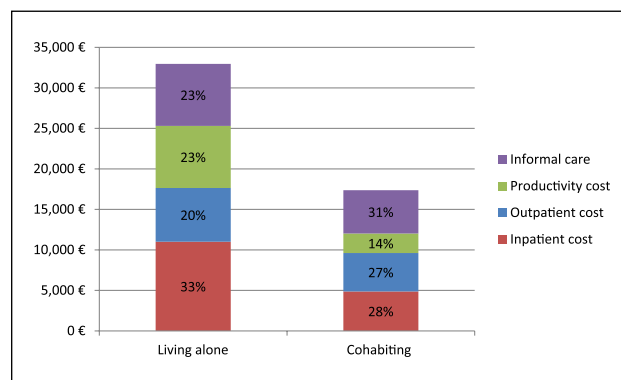
**Figure 2.** Healthcare cost (excluding outpatient medication) in 2-week-periods during the last 12 weeks of life for patients cohabiting and living alone.**Table 3.** Multivariate analysis of cost drivers with the natural logarithm of healthcare cost as the dependent variable.

Variable	Coefficient	p-value
Adjusted R ² = 0.310		
Constant	11.381	0.000
Prostate cancer ^a	0.962	0.001
Breast cancer ^a	−0.624	0.089
Age	−0.035	0.014
Duration of palliative period	0.001	0.055
Higher education ^a	−0.151	0.552
Cohabiting ^a	−0.709	0.010

Boldness means here that variable is significant and the *p* value is <0,05.
^a1: yes; 0: no.

What this study adds

In our study, the total cost of the palliative care period per patient (€21,966) was relatively higher than previously reported. In a recent systematic review by Round et al.,¹⁶ in which the cost of care was estimated for people with cancer at the end of life in England and Wales, the total costs of end-of-life care were €11,202 and in The Nuffield Trust research report by Georgiou et al.,²³ they were

**Figure 3.** Mean costs of patients living alone and cohabiting.

€12,254. However in a recent study by Brick et al.,¹⁰ the cost of the last 3 months (half of the mean duration of palliative care in this study) varied between €26,897 and €30,305, depending on the geographical area. Comparisons between the studies are, however, difficult. First, the cost items included differ. In Round et al.'s¹⁶ study, the HCC covered two-thirds and informal care one-third of the total costs, while in the study by Brick et al.,¹⁰ HCC covered three-quarters of the total costs. Productivity costs were not estimated. In this study, the combined share of informal care and productivity costs covered almost half of the total costs, informal care costs covered 27% and productivity costs covered 18%. The share of productivity costs was even higher (38%) if patients beyond retirement age were excluded. In Georgiou et al.'s²³ study, informal care costs were not included.¹⁰ According to our previous findings,^{24,25} the proportion of informal care increases as the disease progresses from local to metastatic cancer and to palliative state. In this study, the mean weekly duration of informal care received was 11 h as compared to 15 h in Round et al.'s study. Second, in this study, the costs are not estimates, but real patient costs having accrued during the palliative care period.

Finally, the palliative care or end-of-life care period is not uniformly defined. The prior studies have mainly focused on the costs of the last months of life related more to the imminent death than to the purpose of the treatment (disease modifying vs palliative treatment).^{24,25}

In the study by Brick et al.,¹⁰ all the costs of the last 3, 9 and 12 months of life were evaluated and non-cancer patients were included as well. In Round et al.'s¹⁶ study, the end-of-life period was defined from the initiation of strong opioids. In both definitions, expenses of the disease modifying therapies are probably included. In this study, we define the palliative care period as the period of time after termination of oncological life-prolonging treatments to exclude expenses related to specific cancer treatments, and consequently, focus on how palliative care services have affected the costs. Thus, depending on the definition, there is large variation in the duration of the time period evaluated in different studies. The median duration of the palliative care period in our study was 179 days as compared to 243 days in Round et al.'s¹⁶ study and 365 days in the Nuffield report, where the costs of the last 12 months were included.²³

The duration, and thereby the total cost, of the palliative care period varied abundantly depending on the cancer type. In our study, the duration of palliative care period differs from Round et al.'s findings. In this study, the palliative care period was longest in prostate cancer (239 days) and shortest in breast cancer (59 days) as compared to the periods of 360 days in prostate cancer and 372 in breast cancer presented by Round et al.¹⁶ This difference seems to be related to the definition of the palliative care or end-of-life care period. In prostate cancer and breast cancer, bone metastases are present in 70%–80% of the patients with advanced disease. Bone metastases cause severe pain and thus strong opioids are used early in the course of the disease trajectory. This probably lengthened the palliative care period in Round et al.¹⁶ However, the variation in the duration of the palliative care period between the cancer types found in our study is likely to be related to the different nature and oncological treatment options of these three cancer types. In metastatic breast cancer and prostate cancer, the overall survival is much longer than in colorectal cancer, and the treatment options are most abundant in advanced breast cancer. Despite the variation in the duration of the palliative care period, the distribution of the costs in our study was rather similar in each cancer type. Prostate cancer seemed to be associated with highest cost with a somewhat higher share of HCC. We found no cancer type related to differences in costs when only the last 60 days of life were considered. Thus, the difference in costs between the cancer types is largely related to the duration of the palliative care period.

In line with previous studies, the costs of the last 2 weeks of life account for a marked proportion of the HCC²⁶ with inpatient cost being the most significant cost driver. In our study, the proportion of inpatient cost was even more pronounced in patients living alone during the last weeks of life. In Finland, the proportion of single-person households is 22% in the population over 55 years.²⁷ The early palliative care period is relatively inexpensive.

The longer the patients stay at home, the lower the HCC is for society. However, the role of informal care is significant. Support for palliative home care and caregivers could lower the costs of palliative care and fulfil the preferences of many patients, since 80% of people prefer to die at home according to a recent review.²⁸

Strengths and limitations

The limitations of this study include a relatively small and selected sample of participants. Recruitment of patients in palliative care is challenging, which to some extent unavoidably leads to a selection bias towards the healthiest patients. The data on informal care were estimated only at one time point, which could be considered as a limitation. In addition, the time between data collection and reporting was approximately 7 years. However, we do not consider this to have a major impact on the relevance of our findings today, since the general price level has remained almost the same during this time in Organisation for Economic Co-operation and Development (OECD) countries including Finland.²⁹ The strength of this study is the extensive use of cost registers and the fact that the costs are real patient costs that were incurred during the palliative care period excluding costs of cancer-specific treatments. Productivity costs were also available from the registers of SII, and the costs were considerable.

Conclusion

This study describes the true costs of palliative care after the oncological treatments are terminated. The share of indirect cost is substantial accounting for nearly half of the total cost, which highlights the significant role of caregivers. Inpatient costs are significant during the last 2 weeks of life especially among non-cohabiting patients. From an economic point of view, palliative home care should be further developed and focus on caregiver support and the specific needs of people living alone.

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Declaration of conflicting interests

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